DOCUMENT RESUME

ED 455 665 EC 308 630

AUTHOR	Roberts, Richard N.; Akers, Adrienne L.; Behl, Diane
TITLE	Opening Doors through State Interagency Coordinating Councils: A Guide for Families, Communities, and States.
INSTITUTION	Utah State Univ., Logan.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Washington, DC. Maternal and Child Health Bureau.
PUB DATE	1999-01-00
NOTE	37p.
AVAILABLE FROM	Early Intervention Research Institute, Utah State University, 6580 Old Main Hill, Logan, UT 84322-6580. Tel: 800-887-1699 (Toll Free).
PUB TYPE	Guides - Non-Classroom (055) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Agency Cooperation; Community Based Instruction (Disabilities); *Coordination; *Disabilities; Early Childhood Education; *Early Intervention; Educational Legislation; Family Involvement; Federal Legislation; Focus Groups; *Integrated Services; Interviews; National Surveys; Public Policy; Statistical Data
IDENTIFIERS	*Individuals with Disabilities Education Act Part C; *Interagency Coordinating Council

ABSTRACT

This guide describes ways in which partners at the state level can move toward more integrated and comprehensive support systems for children and families eligible for services under Part C of the Individuals with Disabilities Education Act. It reports on the collective experiences of states participating in the "Opening Doors Project," which was funded from 1993-1997 by the Maternal and Child Health Bureau. The purpose of the project was to design, synthesize, and disseminate recommended strategies for integrating services for Part C-eligible children and their families. Information was gathered through extensive reviews of state documents, focus groups, and direct interviews with families, service providers, and state and community-level administrators from six states (Florida, Hawaii, Maine, Missouri, Utah and Washington). Additionally, a nationwide survey was developed and administered to directors of 185 community-based Part C programs that served children and their families through home visits. This guide shares the information gleaned from this work and presents ideas for state interagency coordinating councils (SICCs) to consider as they carry out and refine their own state plans. (Contains 28 references and suggested readings.) (SG)

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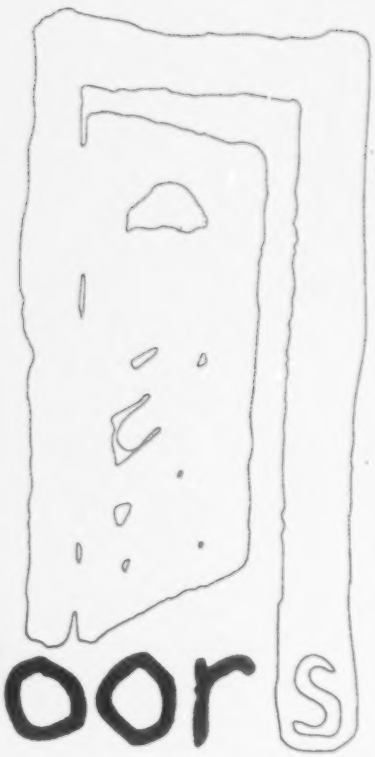

Opening Doors

Through State Interagency Coordinating Councils

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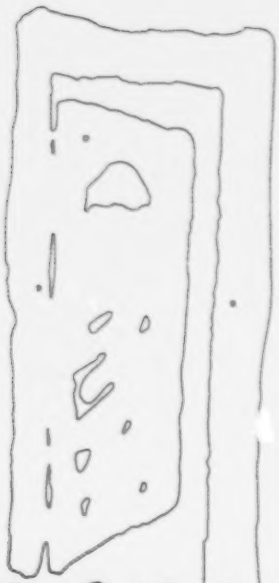
Funded by:
A grant from the Maternal and Child Health Bureau
Public Health Service
U.S. Department of Health and Human Services

Additional copies available from:
Early Intervention Research Institute
Utah State University
6580 Old Main Hill
Logan, UT 84322-6580
800-887-1699

January, 1999



Opening Doors

Through State Interagency Coordinating Councils

A Guide for Families, Communities, and States

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Acknowledgements

From 1993 to 1997, the *Opening Doors* project staff had the opportunity to conduct research in six states across the United States. We are most grateful to the individuals we had the opportunity to work with in Utah, Washington, Maine, Hawaii, Missouri, and Florida. Target communities in each state included Orem, Utah; Federal Way, Washington; Saco, Maine; Hilo, Hawaii; Lihue, Hawaii; Moberly, Missouri; Crystal City, Missouri; and Tampa, Florida. Parents, practitioners, and policy makers in these states and communities welcomed us and provided invaluable information in our study of community service integration.

Although this is not a complete list of all the individuals we met and worked with, we would like to give special thanks to those who participated in the *Opening Doors* retreat held in October, 1994, in Deer Valley, Utah. This lively and enthusiastic group includes Joyce Lacy, Karen Hahne, Kelli Illi, and Linda Stevens of Utah; Rachel Curtis, Nancy Drugge, Sue Motta, and Jane Allen of Maine; Fran Wilber, Kim Barger, Pat Grosz, and John Hall of Florida; Harriet Foiles, Sandra L. Kirtley, and Carla Price of Missouri; Pattie Nishimoto, Suzanne Kashiwaeda, and Rebecca Wessels of Hawaii; and Sandy Murren, Christine Burgoyne, and Kate Willey of Washington.

And finally, we appreciate the support we received from the funding agency for this project, the Maternal and Child Health Bureau. We give special thanks to Dr. Merle McPherson, Director of the Special Health Care Needs Branch, and Dr. Bonnie Strickland, *Opening Doors* project officer. Their support and guidance enriched our work and added credence to our results.

Preface

Young children with and at risk for disabilities and special health care needs deserve a level and quality of service which will maximize the potential for life and achievement. Yet these children and their families continually face challenges associated with obtaining and coordinating the special services they require. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams, and poor coordination among service sectors are barriers consistently cited by families. While some issues may be resolved in the separate programs serving young children with disabilities and their families, most will only be resolved through the concerted effort of the "system of services"—the broad interconnected array of public and private entities serving children and families in our nation's communities.

The Federal Interagency Coordinating Council (FICC), established by Individuals with Disabilities Education Act (IDEA), is intended to identify and promote the resolution of interagency issues and barriers. The FICC's Integrated Services Subcommittee uses the resources of its membership agencies, communities, and families, to identify barriers and to identify successful strategies used by states, communities, and families to address these issues. Programs such as the Early Intervention Research Institute (EIRI), and its *Opening Doors* project, work closely with the FICC to move this national agenda forward. The FICC also works closely with *Communities Can!*, a growing network of communities who share the vision of bringing together all the resources needed to support children with, or at risk for disabilities and their families.

Although programs differ in terms of services provided, our common purpose, indeed our common mandate, is to serve children and families in ways that are coordinated and family-centered. This vision is being translated and operationalized daily in states and communities around the country. Strategies for blending funds, coordinating eligibility criteria and application requirements, coordinating services, and insuring the availability of appropriate health care are emerging and expanding. Our job is to ensure that federal and state policies help rather than hinder this process and that the benefits of these programs are demonstrated in the improved well-being of children and their families. The FICC and its Integrated Services Subcommittee thank the many states, communities, and families participating in this study and the many others dedicated to making family-centered, coordinated, comprehensive care a reality for all young children and their families.

Merle McPherson, M.D.
Integrated Services Committee Federal Interagency Coordinating Council

The Importance of Service Integration

Children, families, communities, states, regions, federal agencies and legislators—all are important partners in developing systems that are responsive to families of children with disabilities and/or special health care needs. Each partner brings unique knowledge, experiences, and an action network of people that can help move ideas into practice. As early intervention programs evolve with new legislation and changes in funding structures for medical, therapeutic, and community supports, each partner's role in the process continues to evolve.

Defining Service Integration

Although the terms *service integration* and *service coordination* are sometimes used interchangeably, they represent two separate issues. Kahn and Kamerman (1992) have clarified the concept of service integration as the "systematic effort to solve problems of service fragmentation and of the lack of an exact match between . . . a family with problems and needs and an intervention program or professional speciality." Service integration, then, is a systems-wide effort with the dual goals of simultaneously improving outcomes for families and enhancing efficiency and effectiveness of human service systems. Service integration efforts focus on several levels, including the family, community, state, and federal.

This guide describes ways in which partners at the state level can move toward more integrated and comprehensive support systems for children and families eligible for services under Part C of the Individuals with Disabilities Education Act. It does so by reporting the collective experiences of states participating in the *Opening Doors* project. The guide also presents ideas that state interagency coordinating councils (SICCs) may wish to consider as they continue to carry out and refine their own state plans.

Generally, private and public agencies at the state level can serve a unifying and organizing role for statewide initiatives. This would be more difficult for federal or community-level programs to manage from their vantage point in the system. States, with the power of state legislatures, advocacy groups, and an increasingly strong role in planning for use of federal block grant dollars, can support creative, community-based programs while ensuring some degree of resource equity.

The U.S. Congress, in its reauthorization of IDEA, has continued to recognize and strengthen the role of integrated services. By establishing SICCs, the federal government acknowledged the central role of state-level private and public agencies, consumer groups, and other partners with a state focus such as university training programs. SICCs recognize the need to continually expand the circle of active participants to more accurately reflect those groups needed to integrate and finance services over time. SICCs are keenly aware that parents and consumers are critical to the planning process and that their voices are heard most effectively when they represent a substantial portion of a council's membership.

The Opening Doors Study

Opening Doors was funded from 1993-1997 by the Maternal Child Health Bureau. This project was designed to define, synthesize, and disseminate recommended strategies for integrating services for Part C-eligible children and their families.

Opening Doors staff used two main procedures to gather information reported in this guide. First, six state Part C programs in six states (Florida, Hawaii, Maine, Missouri, Utah and Washington) served as a consortium to study how community-state partnerships can create family-centered, community-based, comprehensive services. In each consortium state we con-

ducted focus groups and direct interviews with families, service providers, and state and community-level administrators. We also conducted extensive reviews of state documents to understand the concordance between state policies and local practices.

Second, we developed and administered a nationwide survey to directors of 185 community-based Part C programs that served children and their families through home visiting. Participating programs were nominated by their state's Maternal and Child Health Bureau (MCHB) director, their Part C coordinator, or both. Parent groups in each state reviewed the nominations and concurred, or recommended additional programs for inclusion in the survey. The information shared in this guide is the collective wisdom gleaned from this work of the *Opening Doors* project.

Service Integration at the Family Level

Parents served through the Part C system in six states participated in focus groups and responded to the following questions:

1. ***What are the greatest challenges you face in obtaining the services you need and want?***
2. ***What suggestions do you have for improving the service system?***

In a parallel fashion, we conducted agency interviews with state-level administrators and reviewed documents pertaining to agency policies. These sources yielded answers to two main questions:

1. ***What is the role of your agency/department in meeting the needs of children who are Part-C eligible and their families?***
2. ***How does your agency/department work with other agencies to develop an integrated service system to meet the needs of these children and families?***

How Can State-level Policies Begin to Address Family Priorities?

> *"Many families have Medicaid and an HMO, and doctors don't know the system or how to refer. They tend to wait and watch. Some will give the whole nine yards, prescribing PT, OT, speech, when it may not be necessary."*
>
> *A Florida Service Provider*

A *family-centered system* is one that gives families a voice, ownership, and options for services. This means that families are in control of the services they receive. Their input drives program policies and they are represented in system development. In establishing family-centered early intervention programs it is essential to bridge gaps between priorities identified by families and the state and local policies that drive service delivery. This section of the guide examines the priorities of families of Part C-eligible children in six states and discusses ways that state policies and practices have addressed these priorities. Such information enables state policy-making groups, particularly SICCs, to use family-level concerns as the cornerstone of a family-centered service system.

Three parent priorities emerged from the focus groups. Each priority described below is followed by a description of state-level strategies we viewed as responsive to identified needs. These findings provide useful information for both SICCs and Local Interagency Coordinating Councils

(LICCs) as they attempt to build strong family-centered early intervention systems. The list of priorities and strategies does not reflect any particular order of perceived importance.

Parent Priority #1:
Easier Access to the Early Intervention System

Parents were almost unanimous in identifying the need for *greater public awareness of the early intervention system*, including the services and resources available. They described the early intervention service system as a complicated maze. Parents recommended *development of user-friendly information and procedures* on how to maneuver through what they perceived as a confusing process.

Primary health care providers such as hospitals, pediatricians, and family practitioners are a natural referral source for children who need early intervention services. Although parents cited many examples of knowledgeable primary care physicians being the first to suspect a problem in their child's development, others reported that some physicians were hesitant to discuss the possibility of a developmental disability when questioned by the parent. Some physicians had expressed concern about the child's development and had made a direct referral for physical or occupational therapy at a clinic or hospital. Unfortunately, a consequence of referrals to private providers was that families incurred monetary expense. These families were not connected to the early intervention system, which could have offered an additional array of services including care coordination. Several parents stated that they had not learned about other services available through the state's early

intervention system until their insurance coverage was seriously depleted. This not only places the family at risk by reducing their insurance coverage but also delays the development of an Individualized Family Service Plan (IFSP). Supports and services provided by IFSPs help the family as well as the identified child.

It is not our intention to criticize private providers but to show the need for increased public awareness among primary care physicians and other private providers who are unfamiliar with a state's early intervention system.

Responsive State-level Strategies

- ***Connect families with interim service coordinators via central directories and toll-free phone numbers.***

  Part C requires states to develop a central directory to serve as a disability information and resource referral source. This is particularly helpful for families who suspect their child has a delay or disability. Some states, such as Washington and Hawaii, have gone a step further by assigning an interim service coordinator to families when they call the toll-free number. This gives families a personal contact who can provide guidance and support as they work their way through the screening, eligibility, and IFSP process. Once families are enrolled in the early intervention system, a direct service program takes over the role of family service coordination.

- ***Establish task forces on public awareness.***

  Missouri's task force is made up of representatives from relevant agencies serving all children and persons with disabilities. This task force increases public awareness of all human services and helps LICCs organize outreach activities appropriate for their communities. An additional advantage of the task force model is that it recognizes that children with disabilities should be served in the most natural environment. LICC members can help promote this vision of a more universal model of services for all children.

- ***Support public awareness activities via private-public partnerships.***

  Strong, attention-getting public awareness campaigns have been developed. For example, with help from a private foundation in collaboration with a primary television network and others, Utah's *Baby Your Baby* prenatal public awareness campaign was developed. Partners in this effort included the Utah State Department of Health, a local television station, the Utah Medical Association, Blue Cross/Blue Shield, and the March of Dimes. This collaboration resulted in a high-quality, multimedia campaign that targets all pregnant women. It includes a multifaceted media campaign, gift incentives for early prenatal care, and periodic mailings on child development and parenting issues. In collaboration with Utah's Part C Baby Watch Program, the Baby Your Baby hotline links parents who are concerned about their infant's development directly with a Part C program. Such an extensive public awareness campaign would not have been financially possible without the collaboration of various public and private entities.

- ***Train physicians and residents regarding Part C and children's special health care needs.***

  To ensure that physicians can make referrals appropriately, many states such as Hawaii, Florida, and Missouri, have instituted models of physician training regarding the purpose and scope of state early intervention systems. Missouri requires physicians and other medical personnel who have contracts with the Bureau for Special Health Care Needs (BSHCN) to become familiar with the early intervention system. If medical personnel suspect that a child is eligible for the Part C program, they connect the family with a BSHCN service coordinator. Outreach efforts in Florida are directed toward educating pediatricians, but obstetricians have recently become involved. Many states now distribute Part C brochures and posters directly to physicians' offices.

  The state of Hawaii set precedent through development of the "medical home" concept, now supported nationally through the American Academy of Pediatrics. The medical home concept states that there should be a place where a child and his family can count on receiving needed medical care from someone they trust.

The medical home is not a building, a house, or a hospital, but an approach to providing high-quality, cost-effective health care services. The primary care pediatrician of a child with special health care needs works with the early intervention system and other pediatric subspecialists to provide a medical home for the child. The medical home concept emphasizes the role of pediatricians in prevention of developmental delays, and in linking families with family-centered, community-based early intervention resources. Children served within the medical home model, including those children eligible for Medicaid, have a single primary care physician who is attentive to their total health care needs, including overall healthy development.

- ***Link families with universal home visiting programs.***

Missouri's Parents As Teachers (PAT) program is open to all families with children ages birth to five statewide. PAT offers home visiting to all interested families and provides developmental screening, which can alert both parents and the home visitor (referred to as the parent advisor) to a child's need for more in-depth evaluation. Missouri has firmly established this education and support program via a state budget line-item.

PAT parent advisors serve as strong links in Missouri's *First Steps* Part C identification and referral process, and several other states have adopted the PAT model as a way to support new parents. The concept of a universal home visiting program for all families is receiving support from several state legislatures. The MCHB has endorsed it as an important component of a strong prevention effort that supports parents of newborns and infants.

"My service coordinator ties things together. She's helped with transportation needs and she takes care of my billing responsibilities. We've never received a bill. Later, when we need a walker, she'll help us get one."

A Missouri Parent

Parent Priority #2:
Improved Service Coordination

Service coordination is another required component of Part C. We asked families who participated in the focus groups, "Who helps you bring together the services your child needs?" Most families could identify a specific provider who linked them with needed services, but parents did not necessarily refer to this person as a "service coordinator." In addition, the

involvement of a service coordinator alone did not assure adequate communication among providers. For example, an occupational therapist from one agency might not be aware of the conflicting demands placed on the family by a different specialist working for another agency.

Parents expressed frustration with providers who acted autonomously and seemingly without any awareness of competing appointments or the importance of integrating intervention plans. Parents reported that making frequent calls and/or traveling to multiple agencies for service was time consuming and frustrating, especially when they require transporting an infant with special health needs plus other siblings. They expressed interest in having local Part C services and other health/human service agencies gathered under one roof to facilitate parent-to-agency and agency-to-agency contacts.

Parents reported that *duplication of paperwork*, such as family and medical histories required by multiple agencies, is another source of frustration. Parents recommended development of procedures to streamline the exchange of basic information, with the provision of parental consent, across multiple agencies.

Responsive State-level Strategies

- ***Enhance Part C service coordination.***

  Since Public Law 101-476 was enacted, service coordination has played a strong role in the implementation of state Part C services. States must ensure that a service coordinator is identified for each family,

although models of service coordination vary from state to state. For example, Hawaii and Washington hire other parents of children with special needs as service coordinators. In Utah, the person who provides the primary intervention for the child (e.g., a speech-language pathologist, physical therapist, or early childhood special educator) is identified as the service coordinator, with parental approval. Washington, Maine, and Missouri have developed models to ensure that comprehensive services are provided without potential conflict of interest from direct service agencies. These states assign families a service coordinator who works independently from agencies that provide direct services. Service coordinators guide families through the IFSP process and help them identify direct service providers, or vendors, to provide services listed on their child's IFSP. There are pros and cons to each of these approaches. Consumer input should be obtained to determine the effectiveness of the service coordination model being used and the level of consumer satisfaction.

"Collaboration is hard work. When I was growing up no one wanted to play Monopoly with me because I always took their houses and hotels. When we began working with the Children's Village I actually hired someone to coach me in how to work collaboratively. But it was worth it."

A Yakima Fundraiser

- ***Develop common application procedures and interagency data management.***

  To address the problem of duplication of administrative paperwork, several states are developing common application procedures and interagency data management systems. In Missouri, two state agencies are responsible for coordinating Part C services, depending on the child's primary reason for qualifying. These agencies are in the process of developing a system that allows them to accept one anothers' application forms and assessment results, which streamlines the eligibility process.

  Many states are developing interagency data management systems to facilitate the exchange of information across multiple agencies. Washington has implemented a Child Profile system that provides developmental information, data on immunizations, and linkages with other state programs.

- ***Support community "one-stop shopping" models.***

  In some communities in Maine, Missouri, Washington, and Hawaii, health, social services, mental health, and early intervention services are

co-located in the same building or in adjoining buildings. Families can easily access multiple services and resources, such as immunizations and WIC, parent-to-parent centers, and other early intervention services. The co-location of complementary services facilitates co-referrals and improves continuity of care.

In Augusta, Maine, the Vickery is a historic building which houses a unique collection of public and private organizations whose focus is the well-being of children and their families. The Vickery includes programs such as the Children's Museum, a large pediatric medical practice, the local Part C agency, WIC, Big Brothers/Big Sisters, Families First, the Children's Health Collaborative, and the Family Room.

The Children's Village, located in Yakima, Washington, was built through the collaborative fund-raising efforts of several private and public agencies. It also houses a variety of agencies that offer services in a comfortable, family-friendly environment. Services range from pediatric and dental clinics, Head Start, physical and occupational therapists, a family resource center, and an integrated developmental preschool.

When we interviewed members of the fund-raising team in Yakima, one individual commented that "collaboration is hard work." This person's self-awareness and willingness to put the interests of her own organization aside to achieve what was best for the entire community were impressive

- ***Develop state grants for integrating services.***

  The federal government has funded several Substance Abuse and Mental Health Services Administration (SAMHSA) initiatives to encourage states to integrate human services. State System Development Initiative (SSDI) grants, funded by the MCHB, were established to facilitate the development of comprehensive, integrated care systems and improve the health and well-being of children and their families. Community Integrated Service System (CISS) grants, also funded by MCHB, encourage states to enhance integration of their family preservation and public health services, which promotes collaboration in meeting the needs of communities. A product of Florida's CISS grant has been a guide called *A Guest in My Home*. The guide helps communities design a care system that meets their needs and serves as a blueprint for state agencies to follow in supporting community-based efforts.

- ***Facilitate state and interagency communication.***

  Washington's Infant-Toddler Part C program, based in the Department of Social and Health Services, funds liaison personnel positions within the state health department and the state education agency to facilitate communication with Part C programs. Additionally, Washington's Infant-Toddler Program provides funds to county interagency coordinating councils (CICCs) to facilitate community-level coordination. These funds may be used to reimburse CICC families and other participants for time spent in council activities.

Parent Priority #3:
Additional Family Supports

In direct interviews, families described a strong sense of support from their home visitors. They indicated that home visits provide a better opportunity for providers to understand the needs of the child within the context of the family's natural environment. However, many parents reported a need for *additional kinds of support.*

Families repeatedly mentioned that *respite care* was inadequate due to tenuous funding or long waiting lists. They stated that parent-to-parent support was difficult to access in many communities and that opportunities to

> *"Respite is something that I'd like to have back because it helps me. It's been so long since I could just walk to a grocery store alone because I'm afraid to take her. I don't want her to get sick. That's my only worry. If she gets sick I will have to go and stay with her in the hospital, and what's going to happen to my other kids? So we hardly go anywhere where there are lots of people."*
>
> *A Hawaii Parent*

meet with parents who are dealing with similar issues were also limited. Although each state has a Parent Training and Information Center (PTI), funded through the US Department of Education, families with whom we spoke said that their Part C service coordinator did not routinely link them with their state's PTI or other parent support groups.

Mental health services, such as family counseling, were rarely identified as services available to families in the IFSP process. Mental health services in rural areas are especially difficult to access. Interviews also revealed that mental health services representation was limited in multidisciplinary team meetings.

Responsive State-level Strategies

- ***Increase the availability of respite care.***

  Most states have established some type of respite care system. However, in spite of its importance to parents respite care is often one of the first services to suffer the impact of funding shortages. In Hawaii, respite care's partial provision was guaranteed by a decree following a class action lawsuit. The decree requires provision of comprehensive services for children with serious behavioral/emotional needs. Unfortunately, respite care funding for children with other types of developmental delays has been cut severely.

- ***Link families enrolled in Part C with state and regional PTIs.***

  Run by and for families of children of all ages with disabilities, PTIs conduct training and provide technical assistance to parents, especially those who are new to the disability service system. PTIs can serve as critical partners in a state's Part C system by facilitating parent involvement in policy making and by measuring consumer issues related to family-centered services.

- ***Involve parents as staff, co-trainers, and council participants.***

  We concluded that in order to reach all families (particularly those living in rural areas), increased partnerships with parents are needed. Each of the six states' Part C programs employed parents of children with disabilities in staff positions and view parent input as critical in

determining policies, educating personnel and parents, and on advisory boards.

- ***Assure the self-assessment of family-centered practices.***

  Beyond the required monitoring of early intervention programs to ensure Part-C adherence, some states, such as Utah, are providing early intervention program staff with self-study guides to evaluate their use of family-centered practices. Such an approach broadens the state's role beyond simply monitoring Part C adherence to one that assures the enhancement of family-centered practices.

Summary of Responsive State-level Strategies

Some states have broadened their use of family-centered strategies beyond federal Part C requirements. Reviews of state documents and interviews with state-level administrators show that most of these states are developing family-centered strategies that address concerns voiced by parents involved in focus groups. Because all 50 states are required to have a central directory in place, connecting families with an interim care coordinator to help them maneuver through the system is possible. The six consortium states also demonstrated strategies that provide a foundation for successful service coordination, such as common application and data management systems, training for medical personnel who serve children eligible for Part C, and funding to support the efforts of LICCs.

Remaining State Challenges

Hurdles still exist in the development of comprehensive, family-centered services. One finding consistent with past research is the limited involvement and availability of mental health services for families of Part C-eligible children. Administrators and parents with whom we spoke rarely perceived mental health agencies to be active players in early intervention services. Parents continue to view respite care as a valued service, but it remains one of the most tenuous of all services. To discover the reasons for these constraints and to identify potential solutions, state advisory groups such as SICCs would be wise to examine fiscal and regulatory barriers that conflict with identified family priorities.

Service Integration at the Community Level

How Are Some Communities Developing Family-centered Systems of Care?

Besides investigating how *state* systems are creating family-centered services, we studied successful *community-based* strategies. Directors of 185 community-based programs in 49 states that served Part C children and their families completed the *Opening Doors* National Survey on Service Integration. This survey targeted programs that use home visiting to serve children, including Part C-eligible children, and their families. Participating programs were nominated by their state's Part C coordinator, the MCHB director, or both. The state PTI program also endorsed each nomination. Program directors of nominated agencies completed the surveys. To highlight the kinds of strategies used by successful community-based programs, selected data from the survey is presented below.

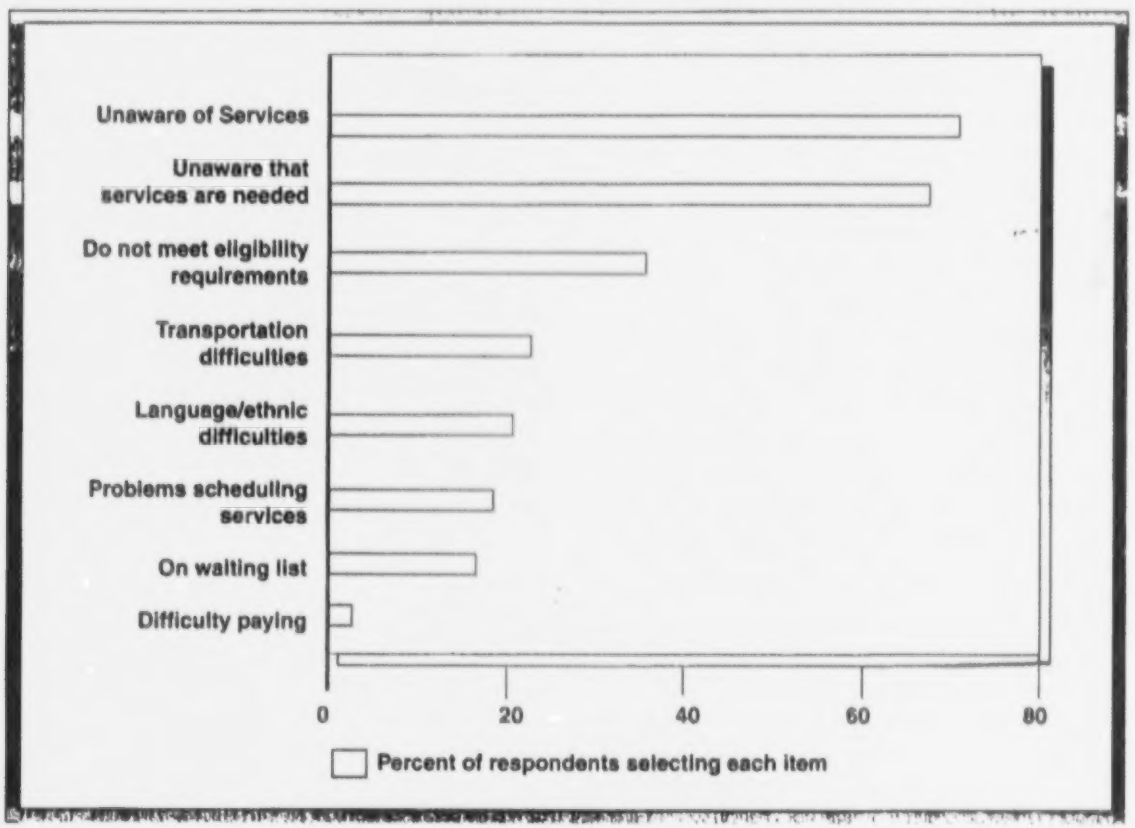

Figure 1. Major factors preventing families from using services.

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Public Awareness Strategies

An important quality of each nominated program was its ability to identify issues that prevent families from using their programs (Figure 1). While factors such as transportation problems, language and ethnic barriers, and waiting lists were rated low as barriers, 68% of programs suggested that many families lack awareness of their child's needs or the availability of services. This finding coincides with the parent priority identified in state-level focus groups mentioned earlier in this guide.

A recent experience of an *Opening Doors* staff member is now something we refer to as the "cab driver test" for evaluating the effectiveness of a community's early intervention services public awareness program. While traveling in Scandinavia a few years ago the staff member asked a cab driver, "If a family moving into your community has a young child with serious health problems or a disability, where would they go?" Surprisingly, the cab driver could describe at length the types of services available and how the family would go about accessing them. Since then we have used the cab driver test to assess public awareness, and to answer the question of whether sufficient information about service availability is so widely dispersed that a casual sampling of citizens would know what is available.

Home Visiting Strategies

According to Table 1, 92% of the programs provided service coordination through home visiting. When asked how much time home visitors spend on service coordination, program directors reported that, on average, approximately 40% of a home visitor's time involves service coordination activities. This suggests that service coordination constitutes a major portion of a home visitor's activity with families in their case load. A significant number of home visitors (49%) also used other methods, such as coordinating services within clinics or classrooms.

Table 1 also shows the breadth of services and resources for children and families served by nominated programs. Many contemporary families have varying work schedules, which makes it difficult to participate in services for the child. We asked nominated programs whether home visits were available outside normal working hours (i.e., in the evenings or on weekends) to accommodate the varying needs of families. Twenty-eight percent of programs reported that they provide home visits outside normal

	Service Provided via Home Visiting	Service Provided by Other Methods	Service Linked With Other Agencies	Service Not Provided or Linked
Direct Services to Families				
Service Coordination	92	49	42	2
Transportation	32	34	67	9
Financial Assistance	19	21	85	10
Respite Care	15	20	68	16
Homemaker Services	9	3	72	23
Job Training	*9*	*8*	*75*	*23*
Parenting Supports				
Enhancing Parenting Skills	92	60	58	1
Enhancing Child Development	90	58	53	1
Direct Services to Children				
Child Screening and Diagnosis	73	51	58	2
Speech Therapy	46	40	65	3
PT/OT	*46*	*40*	*68*	*3*
Health-related Services				
General Health Care	14	21	82	11
EPSDT Screening	11	18	78	11
Prenatal Health Care	11	15	77	14
WIC/Nutrition Services	9	27	83	6
Well Baby Care	6	20	81	9
Immunizations	*5*	*25*	*82*	*6*
Psychological/Emotional Supports				
Informal Family Counseling	77	43	55	3
Stress Management	45	39	64	14
Family Support Groups	28	56	68	3
Professional Mental Health Services	12	22	84	8
Substance Abuse Counseling	11	16	86	9

Table 1. Percentage of programs reporting specific services provided or linked by agencies.

working hours, which indicates a degree of flexibility and an attempt to offer family-friendly services. The fact that this figure is not 100 percent suggests a continued need for programs to reassess priorities. As one agency person described her understanding of the issue, "We need to fit into the lives of families rather than make them fit into our schedules and routines."

Transition Strategies

Families typically need increased service coordination when their child is no longer eligible for services because of a program's age limitations. Many parents first experience this transition process when their child turns age three and is no longer eligible for Part C services. Of the programs surveyed, 75% helped with enrollment into a new program; 26% indicated that children moved from the program's home-based to center-based services. Only 13% stated that they maintained no further contact with the family. With family permission, 62% of the programs sent client reports to receiving programs; forty-one percent contacted families periodically for monitoring; fifteen percent included the child on the state's risk registry or computer tracking system; and 9% of programs maintained contact with the family's physician. Family-centered programs are more likely to incorporate these types of strategies to smooth the transition process for families.

The role of home visitors during the transition process varied, but responses suggest that they play an active role in assuring continuity of services. Fifty-three

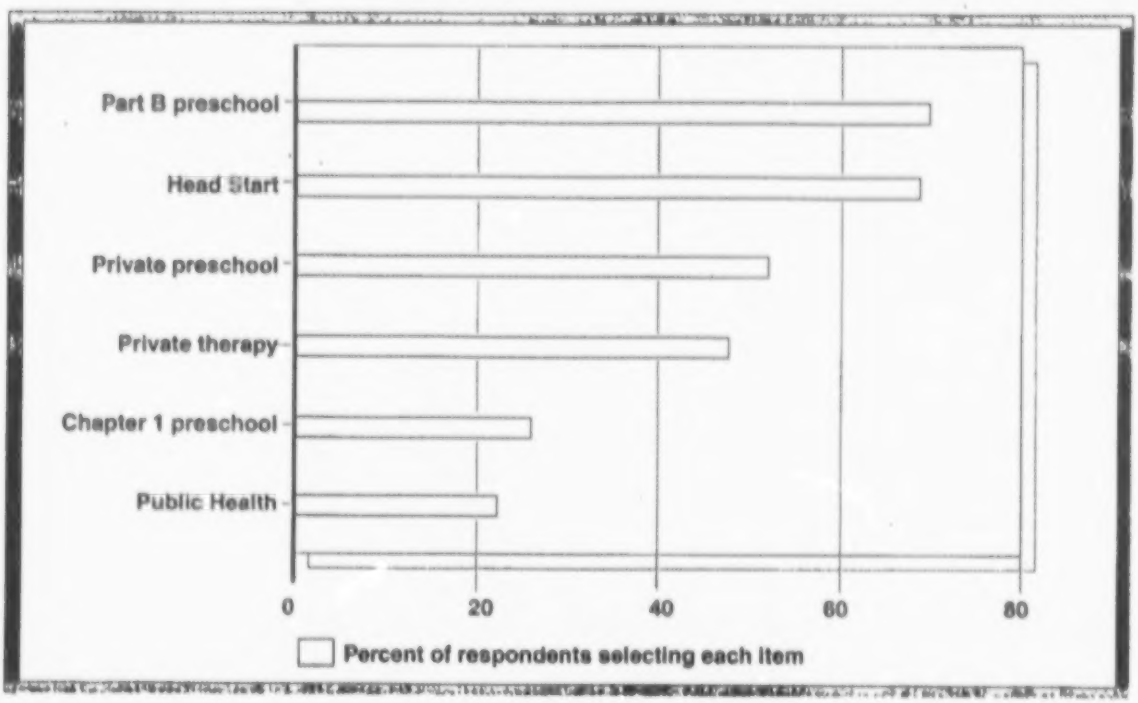

Figure 2. Transition sites for children/families no longer eligible for home visiting program.

percent of the nominated programs indicated that home visitors took the lead in the transition process; 33% reported that home visitors participated, but did not lead; and only 2% said that home visitors did not participate at all. The remaining 12% of respondents stated that families often led the transition process with home visitors playing a supportive role, which implies a flexible role for home visitors in the transition process.

We also asked programs to indicate the specific types of programs to which children are transitioned when no longer eligible for Part C early intervention services. Figure 2 shows that Part B and Head Start programs were the most frequent programs to which children were transitioned, followed by private preschools and private therapies. "Other" responses included community child care programs, home schools, and state-specific preschool programs.

Parent Involvement Strategies

In the programs surveyed, families were not only the recipients of service coordination activities but also took an active role in shaping the programs that provide services. Figure 3 shows the range of collaborative activities used by programs to encourage family participation. Fifty nine

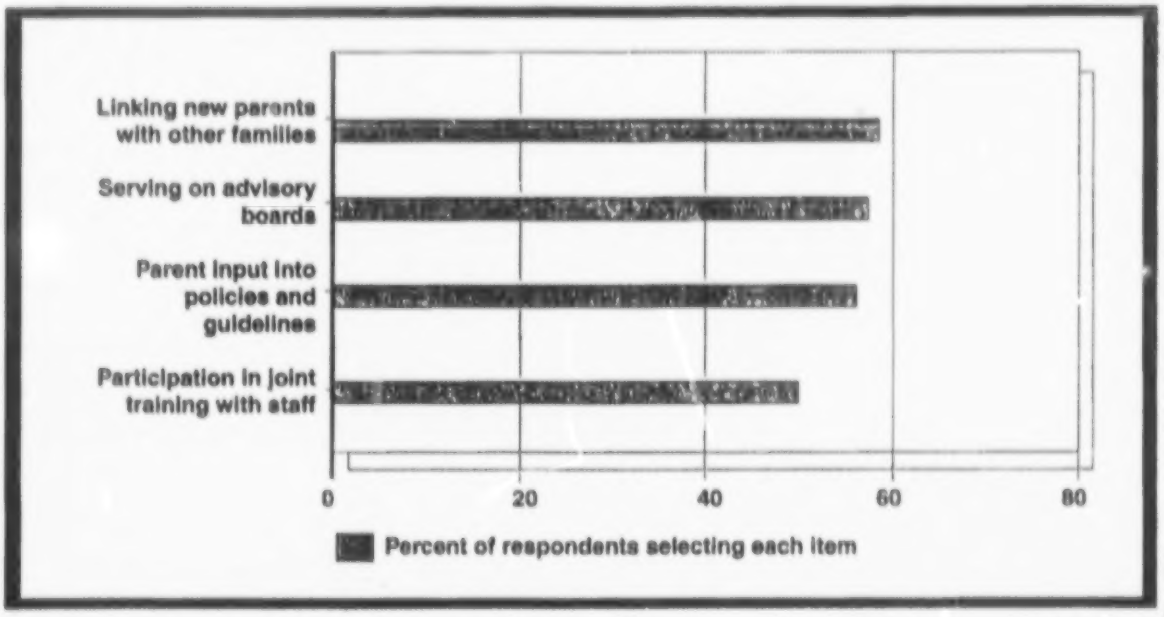

Figure 3. How families are encouraged to collaborate.

percent of nominated programs reported using parents in outreach efforts that link newly-identified families with other families, and 57% of nominated programs had parents on their advisory boards. Parents were included in joint training with program staff, and 56% of programs actively sought parent input in program policies. As programs develop stronger family-professional partnerships over time, these percentages will increase so that active parent involvement will become the expected norm.

Interagency Strategies

In addition to inquiring about strategies used within local programs to integrate services, the survey also inquired about the kinds of strategies used to integrate services *across programs*. Figure 4 depicts 14 strategies that

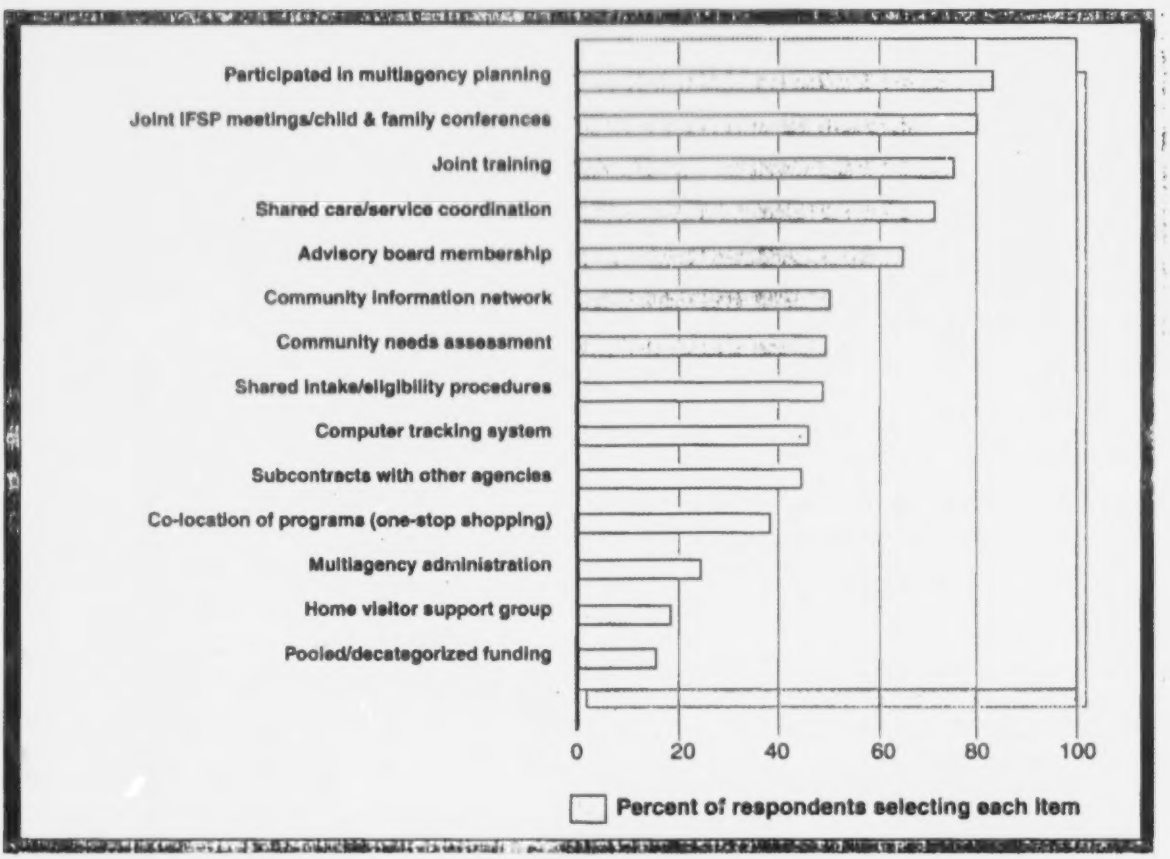

Figure 4. Community-level strategies used to enhance service integration.

programs might use to integrate services across community programs. More than 80% of survey respondents said they participated in multiagency planning (interagency boards or councils) as a strategy to facilitate service integration. However, when asked specifically about the existence of interagency agreements, 23% of respondents reported having none in place.

The service integration strategies reported least often by nominated programs included computerized tracking systems, shared intake/eligibility procedures, co-location of services, and pooled/categorized funding. However, these strategies are cited frequently in the literature as important, if not essential, components to system integration (Kagan et al., 1995; Kahn & Kamerman, 1994).

Nominated programs reported that their greatest involvement was in interagency agreements, interagency councils or committees, shared service coordination, and joint training efforts. These four strategies serve as the hallmark of Part C programs within current legislation (P.L. 102-42), and their extensive use by nominated programs lends face validity to their adherence to important elements of Part C.

Kagan et al. (1995) suggested that local planning councils drive the implementation of integration strategies such as co-location of services, streamlined application procedures, and pooled funding. Data from our survey suggests that although most nominated programs were involved with LICCs, most councils have not yet evolved to the point of implementing more sophisticated integration strategies. Our state- and community-level interviews with LICCs substantiate this finding. State-level support in the form of policy and funding clearly enhances the effectiveness of LICCs.

Service Integration at the State Level

When establishing a system of family-centered system of care, it is essential to bridge the gap between the needs voiced by families and those policies that dirve the delivery of services. This evolution has resulted in state efforts to reform fragmented early intervention and human services to develop a more coordinated system of care that meets that needs of children and families.

How Do Community Programs and State Agencies Typically Collaborate?

Our survey of community-based programs also provides insight into the degree of collaboration between community programs and state agencies. When asked to describe the primary method through which they received support from state agencies, most program directors cited state-sponsored training and conferences. Almost 75% of respondents reported that they submitted state grant proposals to obtain additional funding and that they contacted state legislators on health and disability issues. Sixty-eight percent of respondents reported that they participated in developing general policies or guidelines, and 53% of respondents were members of SICCs.

We also asked how state agencies supported community-level programs. More than 80% of respondents reported that state agencies provided information on state and federal legislative and policy issues related to early intervention/health services, and information on ways that changes might affect families and programs. Fifty-eight percent of respondents reported that state agencies encouraged community-based solutions to local concerns, and 50% reported that their states conducted needs assessments to determine training and technical assistance needs. Less than 50% of respondents reported that their state agencies routinely gathered community input on state policy, helped with referral for in- or out-of-state resources for their families, or provided newsletters to keep programs informed about pertinent issues. Only 26% reported the availability of a state computer-assisted network to access information and resources.

Community Recommendations for State Agencies

We asked community program directors to offer suggestions on how state agencies could enhance their program's ability to better serve children and families. Common suggestions were:

- *Increase funding to support home visiting (e.g., allow the use of Medicaid funds to deliver approved services, such as PT and OT, within the home),*
- *Provide training and technical assistance in service coordination,*
- *Streamline paperwork and data collection requirements via a statewide computer tracking system,*
- *Consolidate intake and eligibility procedures across programs,*
- *Provide flexible funding options, and*
- *De-emphasize "turfism" perceived to exist between multiple state agencies serving children and families.*

The results of this community-based survey suggest several mechanisms that foster collaboration between state agencies and community programs with respect to state policies. Local programs reported that state-level structures give them information needed to operate effectively. Community programs typically learn about state policy changes through mechanisms such as their SICCs. States also make training conferences available for community service providers from multiple programs. This type of collaborative training and support from the state level encourages and nurtures local planning councils for early childhood services, and is a valuable starting point in identifying gaps in local services and developing stronger linkages.

However, community-based programs continue to report that they receive mandates from state and federal programs without the needed

support and two-way communication necessary to implement them. Partnership models between community programs and their state-level counterparts were not reported frequently in our survey. Rather, nominated programs described relationships suggesting top-down administrative styles in which local programs were perceived as unequal partners in systems development. Overall, community programs reported a need for greater state leadership to create mechanisms that would enable them to move beyond less formal methods of coordination into more complex integration methods. Community programs reported that for this to be realized, state guidance and direction is necessary.

Vertical and Horizontal Service Integration

The concept of *vertical integration* illustrated in Figure 5 provides a useful construct for examining how integrated systems develop. Whereas *horizontal integration* implies connections across entities operating at the same level, vertical integration implies conscious creation of linkages that

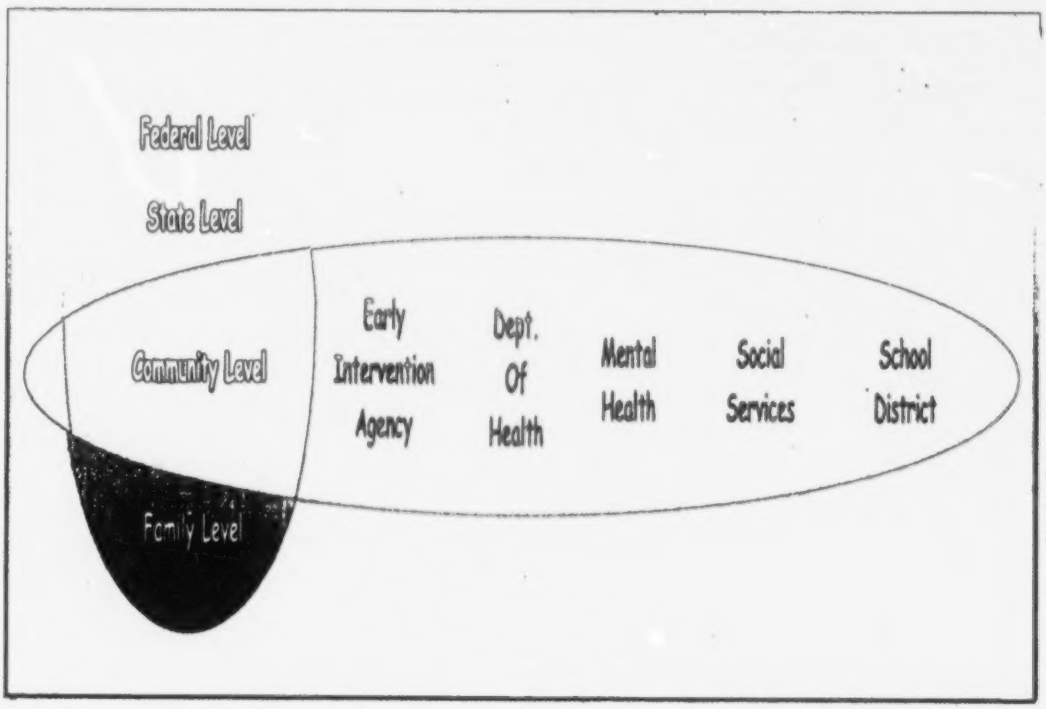

Figure 5. Vertical and horizontal integration diagram.

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connect state agencies and policies to community agencies and their staff (with the children and families they serve). Kagan et al, (1995) found that states in which strategies for integration were in place at multiple levels (vertical integration) were more able to integrate strategies within levels (horizontal integration).

The concept of vertical integration has driven the type and method of data collected by *Opening Doors* staff and was used as a framework in synthesizing the information gathered. Vertical integration ensures more enduring systems change, and states with integrated state policies are more likely to be supportive of integration efforts at the community level. Our work in the consortium states suggests a similar pattern to that reported by Kagan and colleagues.

Service Integration at the Federal Level

What Policy Changes are Needed to Support States?

It is interesting to compare the findings of the *Opening Doors* project with findings of studies conducted during the early years of Part H. In 1992, the Government Accounting Office (GAO) Report on Integrating Human Services evaluated the success of Part H and concluded that this broad-based systems-oriented effort faced many obstacles, met with limited success, marginally altered the way programs planned services, and did not result in comprehensive care. The narrow interpretation was that the integration component of Part H was not effective in improving services for families. However, the GAO conducted its study when most states were still in the planning stage for Part H early intervention programs. Under Part H legislation, states were allowed up to five years of planning before they were required to provide the full range of services mandated under the law (P.L. 102-42). We conducted the *Opening Doors* project after all states had moved from the planning to the implementation phase. Thus, this study provides information substantiating the efforts of programs in moving toward integration of services at the systems level for families.

A study by Meisels, et al. (1988), conducted during Part H's infancy, asked state-level representatives to identify their greatest needs in the area of service coordination. Responses indicated the greatest needs were in case management, staff training, diagnostic assessment, and intervention programs. Barriers identified by the states included funding constraints, inconsistent eligibility criteria, lack of interagency coordination, and inconsistent regulations across programs. Seven years later, results of the *Opening Doors* project show that progress has been made in interagency coordination and case management. However, barriers related to funding constraints, eligibility discrepancies, and inconsistent regulations still exist. These must be addressed through policy changes at the federal and state levels.

FICC Supports for Service Integration

Recently, the Subcommittee on Service Integration and Continuity of Services of the Federal Interagency Coordinating Council made four recommendations related to service integration at the community level. These

recommendations support states in the development of comprehensive, coordinated, family-centered services. States and communities are encouraged to

1. ***pool or blend funds,***
2. ***coordinate eligibility and application procedures,***
3. ***integrate data and information systems, and***
4. ***coordinate early intervention services with the medical home.***

It is important to note that the FICC's recommendations reflect the same themes we encountered in our work with states and communities. Federal policy makers need to hear from consumers and human service providers at the community and state levels. Policy makers are interested in solutions being developed by states and communities and in hearing suggestions on ways to develop federal guidelines that encourage responsive service systems development. Although the FICC does not have specific legislative power, its members can make strong recommendations to the federal agencies they represent.

A unique feature of Part C is the mandate for developing service systems built on interagency collaboration and family-centered practices, to be integrated into each state's existing service system. The states and communities represented in the *Opening Doors* study are moving in this direction. Their experiences offer valuable insight to SICCs as they help communities implement effective service integration strategies at the family level.

References and Suggested Readings

Akers, A.L., & Roberts, R.N. (1988). *The use of blended and flexible funding in Part C programs at the community level.* Unpublished manuscript.

Able-Boone, H., Goodwin, L.D., Sandall, S.R., Gordon, N., & Martin, D.G. (1992). Consumer based early intervention services. *Journal of Early Intervention, 16,* 201-209.

Able-Boone, H., Sandall, S.R., Loughry, A., & Fredrick, L.L. (1990). An informed, family-centered approach to Public-Law 99-457: Parental reviews. *Topics in Early Childhood Special Education, 10*(1), 100-111.

Behl, D.D., Akers, A.L., & Roberts, R.N. (1997, Oct.). Addressing parent priorities through state level policies. *Infants and Young Children, 10,*(2) 26-45.

Bishop, K.K., Taylor, M.S., & Arango, P. (Eds.). (1997). *Partnerships at work: Lessons learned from programs and practices of families, professionals, and communities.* Burlington: Partnership for Change, Dept. of Social Work, University of Vermont.

Brunner, C. (1991). *Thinking collaboratively.* Washington, DC: Education and Human Services Consortium.

Center for the Study of Social Policy. (1991). *Leveraging dollars, leveraging change: Refinancing and restructuring children's services in five sites.* Washington, DC: Center for the Study of Social Policy.

Center for the Future of Children. (1993). *The future of children: Home visiting, 3*(3). Los Altos, CA: The David and Lucile Packard Foundation.

Dunst, C.J., Johanson, C., Trivette, C.M., & Hamby, D.W. (1991). Family-oriented early intervention policies and practices: Family-centered or not? *Exceptional Children, 58,* 115-126.

Halpern, R. (1991). Supportive services for families in poverty: Dilemmas of reform. *Social Service Review, 65*(3), 343-364.

Himmelman, A.T. (1992). *Communities working collaboratively for a change.* The Hubert Humphrey Institute of Public Affairs, University of Minnesota, MN.

Hoover, T.D., Johnson, F., Wells, C., Graham, C., & Biddleman, M. (1996). *A guest in my home: A guide to home visiting partnerships that strengthen families & communities*. Tallahassee, FL: Ounce of Prevention Fund of Florida, Inc.

Johnson, L J., Gallagher, R.J., Montagne, M.J., Jordan, J.B., Gallagher, J.J., Hutinger, P.L., & Karnes, M.B. (1994). *Meeting early intervention challenges: Issues from birth to three*. Baltimore, MD: Paul H. Brookes Publishing Co.

Kagan, S.L., Goffin, S.G., Golub, S.A., & Pritchard, E. (1995). *Toward systematic service integration for young children and their families*. Falls Church, VA: National Center for Service Integration.

Kahn, A. J., & Kammerman, S. B. (1992). *Integrating services integration: An overview of initiatives, issues, and possibilities.* New York: National Center for Children in Poverty.

Mahoney, G., & Filer, J. (1996). Family service activities in early intervention: How responsive is early intervention to the priorities and needs of families? *Topics in Early Childhood Special Education, 16*(4), 437-457.

Mahoney, G., O'Sullivan, P., & Dennembaum, J. (1990). A national study of mothers' perceptions of family-focused early intervention. *Journal of Early Intervention, 14*, 133-146.

Mahoney, G., O'Sullivan, P., & Robinson, C. (1992). The family environments of children with disabilities: Diverse but not so different. *Topics in Early Childhood Special Education, 12*(3), 386-402.

McPherson, M. (1995). *Serving children with disabilities and their families: FICC subcommittee report*. Unpublished manuscript, Federal Interagency Coordinating Council. Department of Health and Human Service, Rockville, MD.

McWilliam, R.A., Tocci, L., & Harbin, G. (1995). *Services are child-oriented and families like it that way—but why*? Unpublished manuscript, Early Childhood Research Institute. University of North Carolina, Chapel Hill, NC.

Meisels, S. J., Harbin, G. Modigliani, K., & Olson, K. (1988). Formulating optimal state early childhood intervention policies. *Exceptional Children,* 55, 159-165.

Melaville, A.I., Blank, M.J., & Asayesh, G. (1993). *Together we can: A guide to crafting community-based family-centered strategies for integrating education and human services.* Washington, DC: U.S. Department of Education, Office of Educational Research and Improvement and U.S. Department of Health and Human Services.

Roberts, R.N., Akers, A.L., & Behl, D.D. (1998). *Opening Doors Final Report: Recommended practices in home visiting integration for early intervention (Grant No. MCJ-495091).* Logan: Utah State University.

Roberts, R.N., Akers, A.L., & Behl, D.D. (1996). Family-level service coordination within home visiting programs. *Topics in Early Childhood Special Education, 16,* 279-301.

Roberts, R.N., Behl, D.D., & Akers, A.L. (1996). Community-level service integration within home vising programs. *Topics in Early Childhood Special Education, 16,* 302-321.

Roberts, R.N., Rule, S., & Innocenti, M.S. (1998). *Strengthening the family professional partnership in services for young children.* Baltimore, MD: Paul H. Brookes Publishing Co.

Summers, J.A., Dell'Oliver, C., Turnbull, A.P., Benson, H.A., Santelli, E., Campbell, M., & Seigel-Causey, E. (1990). Examining the individualized family service plan process: What are family and practitioner preferences? *Topics in Early Childhood Special Education, 10,* 78-99.

Stewart, D.W. & Shamdasani, P.N. (1990). *Focus groups theory and practice.* New York: Sage Publications.